

# Shaping Our Lives

## National User Network

**Panel: Simone Aspis, Peter Beresford, Fran Branfield, Patricia Chambers, Munir Lanali.**

### **A Key Issue for the Future: Relating disability studies to the diversity of disabled people**

#### **Introduction**

The aim of this discussion is to explore the meanings and aims of disability studies and the opportunities and challenges that disability studies offer health and social care service users and service user controlled organisations. We contribute from a diverse range of service users'/disabled people's perspectives ourselves. We include two people who are involved in local black and minority ethnic service users/disabled people's organisations, as well as people with physical and sensory impairments, mental health service users/survivors and a person with learning difficulties. We have experience as campaigners, researchers, teachers/trainers and consultants. We offer this contribution primarily from service users' vantage points, but we hope that it can be seen to have relevance to a wide range of people concerned with disability studies, both as disabled people and non-disabled people and as activists and as researchers/academics. We hope that it may offer a helpful basis for further discussion, particularly for those who may not have had many experiences of engaging with service users.

We feel that diversity is still a problematic issue in the field of disability studies and that it is important to begin to address it in a thorough and systematic way, both to identify the nature of difficulties and as a basis for exploring and challenging them. We are concerned that disability studies should prioritise diversity in its activities and process and for this to be reflected in equal and open access for who can become involved in disability studies. We recognise that there are pressures against this, for example, cultural, academic and economic pressures, but our

concern is that unless disability studies can be as inclusive as possible, then it is likely to be weakened in terms of credibility and academic rigour.

## **Shaping Our Lives**

Shaping Our Lives is a national user controlled organisation which is core funded by the Department of Health. We were established in 1996. We have a track record of undertaking user controlled and emancipatory research and development work, as well as working to improve the support service users receive and increase their say and involvement in their lives at local and national levels. We include and work across a wide range of service user groups, including older people, people with learning difficulties, people living with HIV/AIDS, mental health service users/survivors and looked after young people. We are currently working also to involve people with life limiting illnesses and conditions who are eligible for palliative care services and children and young people who are recipients of health and social care services. We place an emphasis on working in an inclusive and accessible way, to support as wide involvement as possible.

All contributors here are involved in Shaping Our Lives, but most also have other local and national links with disabled people's and service users' organisations.

### ***Peter Beresford***

*Peter is Professor of Social Policy and Director of the Centre for Citizen Participation at Brunel University. He is also chair of Shaping Our Lives. He has written widely in the field of participation and user-controlled and emancipatory research approaches.*

## **Mental health service users/survivors and disability studies**

I write from the perspective of a long term mental health service user/psychiatric system survivor. This is my background and experience. For a long time, I have also worked alongside people with learning difficulties, people with physical and sensory impairments, older people and other groups included in the broader disabled people's movement or identified as long term health and social care service users.

However, some questions are still raised for me as a mental health service user/survivor being involved in disability activities, like this disability studies conference. This is complex and difficult to explain clearly and briefly. Not everyone sees us (mental health service users/survivors) as disabled people. We do not all see ourselves as such. Not all disabled people see us as disabled people – although some do see us as part of a larger and inclusive grouping of disabled people. There isn't agreement or necessarily clarity here. This needs to be acknowledged. There is still a task to explore more carefully what different understandings and views there are on this subject and what significance, implications and meanings they may have. We cannot take people's inclusion as disabled people, or assumptions of commonality for granted.

I want to try and explore these issues briefly here. As mental health service users/survivors, we are and have been subject to a wide range of services, provisions, policies, professionals and legislation. These are generally framed in terms of 'mental health' and psychiatry. These in turn are mainly understood in terms of a medical model of 'mental illness'. This highlights our pathology and deficiency; conceiving of us in terms of what is wrong with us.

Formally, legally and explicitly in the UK and many countries, there are (legal) provisions and requirements which restrict our rights and freedom and which can compel us to receive chemical and other so-called 'treatments'. Recently we have been seen increasingly in terms of risk, danger and threat to 'public safety'. This is now a central part of survivors' experience in the UK, but it is an international development, even more advanced, for example, in some US states and other countries. We have been increasingly associated with violence and extensions of restrictions on our rights and liberty are currently being planned within the UK against wide opposition.

At the same time, in the UK, (although generally we have greater difficulty accessing and retaining them), as mental health service users/survivors, we are also subject to and eligible for a wide range of disability provisions, benefits, services, tax credits and legislation, so that legally and bureaucratically we are often also being defined as 'disabled people. Many of us are included in this way within the terms of reference of disability discrimination legislation and are afforded the protection afforded by the Disability Rights Commission.

Again, this does not necessarily mean that as individuals we see ourselves – or are seen – as disabled people. This is true, even though many people with physical and sensory impairments (who are counted as disabled people) may also have experience of receiving mental health services. Also a significant minority of us as mental health service users/survivors have our own experience of physical and/or sensory impairments (sometimes related to ‘treatments’ and medications we have received). Thus there are significant overlaps between us.

At the same time, there are still many concerns among mental health service users/survivors about being associated with what they see as an additional stigmatising label – as ‘disabled people’. Many are not familiar with the social model of disability and associate disability with individual morbidity, blame and responsibility. Equally the social model of disability does not yet adequately relate to us as mental health service users. In addition, as survivors we have not yet developed an equivalent social model of our own.

We also have our own history and unique sense of who we are, both individually and collectively. Yet many of us closely identify with disabled people and the disabled people’s movement, in terms of the discrimination, prejudice, barriers and restrictions of our rights which we all share.

The medical model of ‘mental illness’ still retains its dominance, even among many mental health service user activists. Now a new idea of ‘recovery’ has been imported from the USA, which seems to be reinforcing the traditional medical model.

So are we disabled people? Are we part of the disabled people’s movement? Are disability studies of concern and relevance to us? Should we be involved in this discussion? The truth is that these questions have still to be adequately discussed. There are certainly no agreed answers to them. Significantly, when Jane Campbell and Mike Oliver wrote their major book about the UK disabled people’s movement in 1996, there was barely a mention of mental health service users/survivors and the only organisation mentioned was an organisation *for* mental health service users, not one controlled by us.

The questions I have raised, I believe do need to be discussed. They need to be explored more generally, but also specifically in the context of disability studies. I for one think the answers to all of them are ‘yes’. Most mental health service users/survivors have as yet not even had a

chance to consider the questions. Disability studies needs to be supportive of helping this happens. It needs to encourage the discussion. This is another reason why it is important to place an emphasis on it being as accessible and inclusive as possible.

We want to argue here that the relationship between us as mental health service users/survivors, other service users and disabled people, needs to be examined and explored. We personally also think it needs to be strengthened. We want to make explicit that we increasingly identify as a distinct part of a broader disabled people's movement.

We want to highlight the importance of disability studies and any Disability Studies Association including the issues relating to mental health service users/survivors and the other groups we include, equally and fully as part of their focus, process and activities.

As I have said, there will be pressures against this. These may relate to existing divisions and the difficulties addressing these; for example, between people as disabled people/non-disabled people; mental health service users/non-mental health service users; disabled researchers/non-disabled researchers; researchers/activists; academics and non-academics. Such pressures need to be identified, worked through and challenged. They must not be allowed to be taken for granted, reinforcing traditional exclusions and inequalities. Disability studies and associated groupings and initiatives, need to identify equal access and inclusion as a core principle for their ethical and effective development and operation.

## **References**

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- Campbell, J. and Oliver, M. (1996), *Disability Politics: Understanding Our Past, Changing Our Future*, Basingstoke, Macmillan.

### ***Patricia Chambers***

*Patricia has been a user for nearly 15 years. She is very passionate about user involvement, and feels it is the way forward. She is heavily involved in*

*planning services with WLMHT and the PCT. As a black user she is also very interested in the fate of black mental health.*

## **The complexities of ethnic identity within the context of Disability Studies**

Good after-noon, I'm Patricia Chambers and I am the co-ordinator of a Black user group in the borough of Hammersmith and Fulham in London. We like to call the group BUG's for short. I am also the user representative in planning meetings run by the local authorities, namely the SCG (Strategic Commissioning Group) and LiT (Local Implementation Team meetings) I am also a trustee on a charity for the Mentally Ill and victims of Aggression, I'm deeply involved in User involvement with a focus on Black mental health.

Today's topic evoked a lot of thought from me "Relating Disability Studies to the Diversity of Disabled People" and in particular the complexities of ethnic identity within the context of Disability Studies. I won't attempt to lecture on this topic but to hopefully affect some thought.

Questions came to mind like "What should Disability Studies be aware of with minorities, what practical benefits do minorities get from Disability Studies, how does Disability Studies deal with issues such as multiple identity and oppression and what can be done about and with the findings from Disability Studies. Minorities live with circles of fear, we are afraid of standing out anymore than we already do and the majority are afraid of change, and that which is different. A recent report by the Sainsbury's Centre for Mental Health talks about these circles of fear focusing on the Black and African community. Stating that while it is widely recognised that we are over-represented in mental health services our general experience is poorer than our white counter-parts, leading to a reluctance on our part to use the services and ask for help or comply with treatment, which increases the likelihood of a personal crisis, leading in some cases to self-harm or harm to others. This in turn reinforces prejudices and coercive responses, resulting in the down ward spiral in which staff see service users as potentially dangerous and service users perceive services as harmful and controlling. But just because there is low involvement

it does not mean that there is low need. Numerous Disability Studies of ethnic minorities support this view. There needs to be a committed overhaul of the services accounting for ethnicity and culture. Not only are we likely to be excluded from society because we are disabled, but we are also excluded because of our race. Studies have shown that exclusion is a major contributing factor to mental ill health along with things like poverty and under achievement in education. Things that are rife in the black community especially among afro-Caribbean males, who suffer high exclusion rates from school, which leads to unemployment or low paid jobs and then inevitable poverty. Studies have also revealed that ethnic minorities feel that their voice goes unheard or very little notice is taken of what they have to say. We are the weak and the vulnerable. The treatment of us reflects tellingly on a society. What benefits do ethnic minorities get from Disability Studies? Hopefully a Disability Study will bring awareness to the majority of the problems ethnic minorities have. Hopefully disability studies will bring about understanding and empathy. Hopefully Disability Studies will bring positive change. Hopefully Disability Studies will stimulate progress. As yet it still has to have an effect on the lives of individuals that are the subject of the study. A study is a chance to talk and air problems and however small the chance it's better than no chance at all. Minorities have willingly taken part in studies in the hope that something can be done. We are eager for change. Change would be good not only for us but for society as a whole. On a number of occasions ethnic minorities have voiced that studies have not taken into account the fact that as individuals they suffer from a multiplicity of 'ism's' and oppressions for example, racism, sexism, ageism class and culture differences, etc. all at the same time. We can all identify with this variety of labels as, for example; you can be a mother, an auntie, a sister and a daughter all at once. Being under attack from so many angles worsens the impact of being disabled. By not taking into account the many identities that any one person may have could negate the findings of any one study. Researchers may miss major contributing factors for example a black disabled woman may not get a job because she is black, or because she's a woman or because she is disabled. The study may only pick up on the disability. This gives in reality a distorted view of what is really happening. The definition of Black has to be more precise as in the current climate anything that is non-white is classified as Black. This is an abuse of Black, telling us that anything can be black and reinforcing opinions that black is not special or distinctive.

Oriental and Asian people have an experience that is uniquely different to Black African and Caribbean. Our cultures and customs are different and our experiences of western society are different. This all needs to be taken into account when defining us.

Studies have highlighted the difficulties of disability and some of the complexities of being disabled and of an ethnic minority. There are numerous recommendations on how to improve the lot of disabled minorities, but little has been done on a practical level. Little has been done to facilitate real change, change that we can see in our every day lives.

To improve services long-term support of ethnic minorities is required and a major part of that support needs to be long term funding for black projects and black organisations. The marginalisation of black projects and black organisations needs to stop. There needs to be a work force committed to taking forward the work with disabled minorities. Black people need to be employed in positions of influence where they can effect change and progress and not just be tokens to ease consciences. There needs to be direct work with black disabled people and if they so wish their families. Staff need to be trained on race and disability and there needs to be joint-agency working across black organisations and disability organisations. Workers need to be educated on our specific experiences and needs. We need studies that will produce change in the everyday life of the ethnic minority disabled person.

## ***Munir Lanali***

*Munir has been using services for the last 20 years within Greater Manchester. He was a founding member of Awaaz. His main interests are in user involvement, particularly in relation to ethnic minority issues and user controlled services. More recently he has taken user controlled organizations a step forward by setting up an Asian cardiac users group called Achi Zindagi (good life).*

## **Effective user involvement**

### **My background**



I am a user/survivor of the psychiatric system. I am also a user of cardiac services. I set up a group for South Asian users of cardiac services called Achi Zindagi (good life), which was the first of its kind to be run and managed by Asian service users. I am an activist for black and ethnic minority service users.

### **What is effective user involvement**

User Involvement means making sure that the user is valued for his or her experience. It means that they are paid for sharing their experiences and reimbursed for all costs incurred. This includes such things as support costs, travel costs, out of pocket incidental costs, such as taxi fares, telephone costs for emails, and lastly carers costs for caring for someone.

### **Accessibility**

The meeting has to be accessible. This is carried out by making sure the venue is accessible and that the format of the meeting is accessible. It is important to make sure the user doesn't have to overly exert themselves, and to make sure there are enough breaks. It also means that at the event the information is in an appropriate format this might include providing material in large print, in different community languages in the case of ethnic minority community, providing signers or interpreters. It also means that there is variety in food such as halal or vegetarian, and making sure the various types of food are clearly labelled and separated. However, don't assume that because you have translated something into a community language you have done your job. I know of an incident where a housing association translated some information and then displayed it the wrong way round. Only after nearly a year did someone mention that it was the wrong way up. Or another example of an accessible toilet that was only accessible for able bodied people or for people of a certain size.

### **Shadowing/ mentoring**

This is done by making sure the user feels well enough to participate, and that there are last minute substitutes to take the users place if the nominated service user cannot make the meeting. It is also about making sure that the user feels comfortable if it is their first time speaking to psychiatrists or consultants at a meeting, and it is about making sure the user is aware of all the issues, so it is good if the service user can be met an hour before the meeting.

## **Supervision**

A service user must have independent supervision, at least once a month. Sometimes it might be necessary to have supervision more often. The organisation he/she is working for should pay for this.

## **What is not user involvement?**

Giving a service user their BFH (bus fares home); giving the previous minutes to a service user 30 minutes before the meeting, or giving sandwiches and expecting the service user to be thankful for a day out and lunch – these are not instances of good practice.

## **Why involve users?**

First, if it were not for people who were 'mad' then half the professionals would be out of a job!

Secondly, this is part of Tony Blair's flagship called 'patient and public involvement'.

## **Some concluding remarks**

User involvement and social inclusion is not rocket science. All it takes is for someone to think differently and think of me as a human being and look at my ability rather than my disability or the colour of my skin or my walking stick

### ***Simone Aspis***

*Simone is a Disability Rights activist. She has undertaken a wide range of research projects. She has written many papers and articles around self advocacy, issues around learning difficulties and on the topic of inclusive education.*

## **Involving People with Learning Difficulties in Research**

There is a lot of talk about involving disabled people with learning difficulties in research. This is a big and serious issue. There is an assumption made that people with learning difficulties cannot complete or control the whole research process themselves. It is assumed that we cannot be involved in deciding what we want to

do research on, the hypothesis, right through to the designing of the research, the methodology, designing the questionnaire, doing the analysis and then making recommendations and designing the theories to understand our relationship to the world as disabled people, or in any other way.

There is an assumption made a lot of the time that just because some people with learning difficulties can not do research then all people with learning difficulties can not do it. These kinds of assumptions are not made about any other group of people. So, for example, because some unemployed people, or some black people, might not have the experience, the skills or the knowledge to be involved in all parts of a research project, no one makes the assumption that no black people or no unemployed people can do user led research. So the same assumptions are not made about other groups of people but they are made about people with learning difficulties.

I think there is a big power struggle between three groups of researchers – non disabled researchers, disabled researchers without learning difficulties and disabled researchers with learning difficulties. The whole premise of research, it seems to me, is based about this idea of ‘academic rigor’. Now both disabled researchers with out learning difficulties and non disabled researchers are quite happy to uphold the status quo. At the end of the day they get prestige. Most people do not get PhD’s and therefore do not get into the academic research field, and so I feel the two groups are in cahoots.

This is unfortunate because it means we cannot turn round to our disabled academic friends for any support. At the end of the day disabled researchers without learning difficulties and non disabled researchers have a vested interest. At the end of the day they have mortgages, they have kids, they have holidays they want to fund etc. etc. so why on earth would they want to look out for us.

What I want to say is that people with learning difficulties can do research, they should have their research validated by the academic field. But other researchers want to keep them from being involved, and say they can not do research basically because they do not have a PhD.

Another aspect that I think is a problem around involving people with learning difficulties in research is that there seems to be a lot of lying going on. When disabled people with learning difficulties are involved in academic research there seems to be very little ethics involved. For example, I know of a researcher who claimed that he had four people with learning difficulties advising him on the social model of disability. Now, as it happened I knew three of these four people. I asked them about this work and said I believe you are advising this person on the social model of disability for his research. They said that was not what happened at all. They said that he had interviewed them about their life stories. It seems to me that many researchers pretend that there is greater involvement of people with learning difficulties than there often is. The point is that no one questions this. When it is brought up, it is not even defended because there is the assumption that the researcher involved them in the only way he could. But in no other area would interviewing people mean involvement. Advising is when you look at the whole picture, and you look at the data, you look at all the information, you are advising the researcher on how to proceed or whatever. Interviewing someone is quite different. There is so much bad practice going on when researchers, disabled or not, claim to be involving people with learning difficulties. And no one seems to want to question this. There seems to be one set of research ethics that everyone uses except for people with learning difficulties. When people are researching into some part of our lives then the researchers seem to have no ethics at all. Anything goes. Again this comes back to the assumption that people with learning difficulties cannot do research. There is always going to be people who can do research and there is always going to be people who cannot do it. That is true of all people. You cannot make the assumption that disabled people with learning difficulties all cannot do research.

Another point is that when researchers who do not have a learning difficulty select people with learning difficulties to be on an advisory group, they often do not use the criteria they would use if they wanted an advisory group of people without learning difficulties. For example, when people invite people to be on an advisory group, they choose people who have the appropriate skills and knowledge so they can give useful advice. But when people want an advisory group of people with learning difficulties, they ask any person with learning difficulties, even though there might be people

who know about certain things. They don't think that people with learning difficulties can know anything.

When people with learning difficulties have done research it is not often cited or recognized by other academic research. Academic researchers only seem to recognize research that comes from the university sector.

When people with learning difficulties try to become students and do a course they are kept out by not having the right academic qualifications. This is not the same for disabled people without learning difficulties. Many disabled people without learning difficulties have got on to courses on the basis of their personal experience and not qualifications. This is not the case for people with learning difficulties. I am not saying that people need a degree or whatever to do research but people with learning difficulties at every corner experience barriers to being involved in an equal way in research.

We need to be looking at how we can make the whole research process more inclusive. This should not mean that we all follow the same approach. We should be looking at how to make research much more open to all people who want to do it. We need to find ways to support people with learning difficulties in the whole research process. What's good for disabled researchers with learning difficulties is good for the whole research industry.

***Fran Branfield***

*Fran is Manager of Shaping Our Lives. As a Research Fellow at the Centre for Citizen Participation, Brunel University she has undertaken user controlled research projects on disabled people and empowerment and on disabled people's perspectives on 'Do Not Resuscitate Orders'. She is also a freelance disability consultant, researcher and trainer.*

**Key Issues for the Development of Disability Studies**

I want to talk very briefly about the importance for the future development of Disability Studies of ensuring grass roots involvement. Disability Studies has to be centred on disabled people in the broadest definition. This does not and should not mean that it is only 'done' by disabled academics, although I believe that the only academics doing disability studies should be disabled people, but more fundamentally I don't think it should be carried out only by academics. If Disability Studies is to reflect the experiences, knowledge and day-to-day reality of disabled people in order to explore and develop theoretical tools and promote debate then we don't just want our voices heard in order to support academia. We want theory, research, evaluation - a discipline that will change for the better the lot of disabled people. Otherwise what is it for?

This means that Disability Studies must be able to be 'done' by grass roots organizations of disabled people. This is not the same as academics disabled or otherwise 'parachuting' in a few disabled people to give credibility to their work. This means making sure that Disability Studies is open to all disabled people to have their say in influencing the agenda, in arguing the theory and thus in effecting the practice. Disability Studies needs to be owned by disabled people.

It is fashionable at the moment for the government, in various guises, to 'consult' with service users. At Shaping Our Lives we are constantly invited to take part in consultation processes, involvement initiatives, and the drafting of good practice guidelines. Many of these look very tempting, but the reality is that the majority of them do not want to listen, acknowledge or learn from service users. We find this out very quickly and simply. We tell them how much it is going to cost to involve in a meaningful way, service users. That is we tell them our principle of paying service users a realistic fee for their time, knowledge and expertise. We tell them that we expect all travel and any personal assistance or support workers costs to be met in full and we explain what we mean by meeting everyone's access needs. From the reaction we get to this we can tell if they seriously want to involve service users.

These points are very important for the development of Disability Studies.

Let's take this conference. It is costing Shaping Our Lives a considerable amount of money (which incidentally we don't have much of) to ensure that five of us could attend and speak here today. Whilst we have two free places allocated to us we still have to find the fee for three more people. But also we have to pay in line with our principles for service user involvement and we will be reimbursing the costs incurred by all members of this panel. This prohibits our involvement in most academic conferences, and obviously stops other disabled people from attending at all.

I know it is rather boring and mundane of me to start talking about money in this way. But it is absolutely essential that these financial issues are addressed in a real and positive way if disabled people are going to be central to Disability Studies.

Disability Studies is different from other academic disciplines. It is a relatively new area of study, and what we understand disability to be, grew out of the disabled people's movement. It was disabled people who developed the first theory of disability that has equality and civil rights as its cornerstone. As theory develops so too must Praxis

We are all familiar here with the notion that what disables disabled people is the policies, practices and attitudes of a disabling society. And yet do we here such basic issues being discussed as how Disability Studies is going to develop a policy on access. In its widest possible sense. Even in a setting where there is a lot of disabled people access can have a very narrow meaning. Not only should physical access be addressed but policies and procedures need careful examination to ensure they do not exclude anyone. Timing is an access issue which is often overlooked, as is the language we use, and quite crucially for many disabled people is an inclusive and friendly atmosphere.

So a crucial question that I feel needs to be asked is: Does Disability Studies remain loyal to its roots, to the founding principles that were developed by the Union of Physically Impaired Against Segregation (UPIAS) which were the beginnings of the modern Disability Movement and if so how is that compatible with academia?

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